What Would Recovery Oriented Research and Publishing Look Like?

(2010)

I am just old enough to remember when doctors were supposed to learn from their patients: When the mark of a good, experienced clinician was a wealth of stories and wisdom that they had collected from carefully listening to their patients over years of practicing their craft. I am also just young enough to have been taught to ridicule that approach: to learn that it was old fashioned, easily distorted, that a string of anecdotes is not data, and that the only reliable knowledge comes from research studies that control for bias, preferably double-blinded controlled studies. I was taught that the mark of a responsible clinician was that they kept up with the literature, that they kept a stack of medical journals by their beds for evening reading.

By now this shift appears almost complete, but is it really? How do practitioners actually learn now? Do we read that flood of journals that come to us filled with pharmaceutical advertisements, or do we still learn mostly from our patients? I don't know.

I do know that this shift, from patient based learning to research based learning has caused an important, but rarely discussed shift in the doctor – patient relationship. Although most grieve the loss, patients no longer really expect their doctors to really listen to them carefully to figure out what's wrong with them and then listen carefully to figure out how the treatment is working, learning about the patient, their illness, and their treatment in the process. Instead, they expect us to diagnose them using some objective tool and give them the latest scientific treatment that the researchers have discovered. We're expected to apply "evidence based practice" to their case. The crucial component isn't the doctor - patient relationship; it's the "informed guidance" researchers give to practitioners. Are researchers really able to accept that burden of responsibility? Do they really create enough knowledge to treat people successfully? Do their discoveries work in the real world with real patients?

And what happens when the patient learns about the "newest discovery" before their doctor? Many important studies are now released in the popular media and discussed on the internet before the journal article actually gets to our office. Many "new advances" are marketed directly to the consumer. Have we come so far that the main reason to listen to our patients is to learn what the researchers have discovered we should do?

Let's take a breath and back up a step. The main reason for replacing clinical learning with research is the risk of bias in clinical learning. I might be inclined to use a new drug because the drug representative was attractive, or gave me gifts. I might think that a particular treatment is effective because a favorite patient did particularly well. My own beliefs about a particular illness or treatment might affect how well I think it works, or even how well it actually works in my practice. (For example, when I was a psych resident, I thought that it was very important to get young people with schizophrenia to take antipsychotic medications, but not so important to get people with borderline

personality disorder to take medications. Therapy is what helps them. The very bright resident in the office next door thought that medications weren't crucial in the early stages of schizophrenia, social skills training was, but that mood stabilizers and antipsychotics were crucial to improving the emotional lability of people with borderline personality disorder so they aren't repeatedly retraumatized. By the end of our outpatient year, both of our sets of patients were receiving different treatments, and mostly doing well, and we were both convinced we were right and the other one was wrong.)

The "clinician's illusion" is a very real and very important phenomenon that effects our practice every day. It effects the entire recovery movement profoundly: There is a set of well done research articles that "prove" that most people with schizophrenia recover over time. Arguably, the best of these studies is Courtney Harding's 20 year longitudinal follow-up studies of people with schizophrenia who were released from the state hospitals in Vermont and New Hampshire that documents that the majority of them no longer have disruptive symptoms or are in treatment and they're living independently, working productively, and have a social life indistinguishable from their neighbors. They've either dramatically improved or actually recovered. But very few practicing clinicians believe these studies or tell their patients about them. To be honest, very few clinicians have even heard of these studies. Why? Because, in my mother's words, "When I believe it then I'll see it." Clinicians spend our time with a highly biased group of people with schizophrenia – those who are not recovering.

Let's take a more mundane, but perhaps more typical example: Both of us and most other clinicians believe that Geodon is not a very effective antipsychotic and therefore don't use it much despite its favorable side effect and safety profile. We believe this despite the fact that there are research studies that "prove" that it works as well as any other antipsychotic. One possible reason for this difference in perception is that Geodon was released after the other atypical antipsychotics and its promotion campaign wasn't nearly as aggressive as the others. As a result, very few clinicians use Geodon as our first line antipsychotic. Instead we give it to patients who are dissatisfied with our first choices to see if it will work better. That's a biased patient sample that's likely to respond less well and lead us to the conclusion that Geodon doesn't work very well. (By the way, isn't that the same biased sample that was used in the CATIE study leading to the conclusion that none of the atypical work very well?) Another possible reason for the difference in perception is that the research studies were systematically biased by the pharmaceutical company seeking to market and profit from Geodon regardless of how well it actually works. Many clinicians wonder if we should really trust research studies more than our own perceptions.

Clinical trials claim the high ground primarily because their scientific methodology "controls" for observer biases. We were taught in residency how to read studies "critically" to determine if a study's methodology really is valid and therefore trustworthy. Unfortunately, over the years, the statistical and research methodologies being used have grown in complexity and I don't have any great faith that I can tell by carefully reading an article if it's methodology is trustworthy

There are other ways of earning clinicians' trust. For example, I prefer going to conferences to reading papers because I can get a sense of the person when they're in front of me speaking, making small talk, and answering questions, all of which is systematically removed from published articles. (By the way,

this is how I earn my patients' trust, not by dazzling them with my intellectual accomplishments.) Most researchers are far more engaging and "applicable" in person than in their articles.

As I alluded to above, trust can also be about assessing motivations. Even when I'm not being cynical, it's possible to imagine a lot of reasonable motivations that researchers may have besides guiding my practice so I can help as many people as much as possible (e.g. to get published, tenure, research grants, funding from pharmaceutical companies, respect form research colleagues, to discover underlying biological mechanisms or to develop explanatory mathematical models). I really don't know how much of the goal of researchers is to guide our practice. I've seen over 20 years of research announcements about the latest genetic basis for some mental illness and been shown increasingly sophisticated, colorful brain imagery and yet I can't think of a single psychiatric patient I ever helped using psychogenetics or brain imagery. Why are these fields so well funded and apparently so exciting to researchers when I'm not finding them useful to help my patients?

We'd recommend exploring two approaches to improving the usefulness of clinical trials: 1) Alter research methodology, sacrificing some "scientific objectivity" to address more applicable clinical and recovery issues and 2) Improve the "engagability" of research products.

1) Research methodology:

Ken Wilber describes in his books in incredible detail a familiar hierarchy of levels of complexity that exist within all of us going from physical to chemical to biological to psychological to several levels of spiritual. At each step up this evolutionary ladder a new layer of complexity is added that cannot be described at the lower level. For example, the quality of being alive is not just a chemical process and God cannot be understood by psychological processes alone. The scientific method is at its most powerful and effective the lower down the ladder we go. Psychologists are not less successful than physicists because as Richard Feynman suggests, they're too lazy to work hard enough to really know anything for sure, but because the complexity of psychology is inherently more difficult to understand using the scientific method than that of physics. It seems to me that most neuropsychiatric researchers drift to the neurological rather than the psychiatric because it is easier to apply the scientific method there.

This research tendency to reductionism has already had profound effects on our clinical treatment system. In the battle between the psychoanalysts and the biologists a few decades ago, researchers played a key role in proving the effectiveness of biological treatments. In my opinion, that support was probably as much because biological reductionistic treatments are easier to study than highly individualized, psychological therapies as because they are actually more effective. Biological treatments were more "demonstratably effective". It's unknown whether they're actually more effective (that title probably belongs to moral treatment as it was practiced in the 1800s, but that on an even higher step than psychotherapy, so it's even harder to study scientifically). It's really very difficult to be confident that the present biological practice, giving millions of people after cursory evaluations and modest treatment relationships lifelong medications with minimal attention to their trauma,

relationships, substance abuse, culture, poverty, or personal motivation, insights, or goals is actually an effective practice.

At the present time another challenger to biological treatment is emerging – the recovery model. The recovery model is a highly individualized, holistic, value based approach to treatment. Its goal is not just the treatment of illnesses, but helping people with destructive illnesses have better lives. It focuses as much on the crippling effects of illnesses as on the illnesses themselves, on stigma as much as symptoms, on opportunity as much as function, on strengths as much as weaknesses, on isolation as much as insight. It actively incorporates resilience, overcoming trauma, personal subjective reactions, collaborative treatment relationships, family and social support, cultural and even spiritual resources.

Recovery exists on a higher step of the hierarchy than the medical model – Illnesses don't recover, people do. It seems likely that history will repeat itself and reductionistic researchers will actively support the medical model over the recovery model primarily because research methodology is a better match with medical model practice. If recovery is to have any substantial chance of being supported by research a good first step would be for research to attempt to be more holistically clinically applicable.

A couple examples: Seroquel often has an initial effect of being sedating. My clinical application of this fact is that I should take advantage of this to give it to people who have not made a commitment to long term medications and treatment who might become more motivated if they experience some relaxation or better sleep now and I should avoid giving it to people who are afraid of being labeled as mentally ill and "drugged up." Resperidal Consta injections seem useful for people who are too irresponsible to take pills regularly, but may be more stigmatizing than taking pills and more likely to cause people to disengage from treatment entirely so I should convert to pills as soon as possible. Both of these "typical" clinical situations involve me assessing personal "subjective" variables (fearfulness, responsibility, and engagement) rather than "objective" characteristics of their illness. To guide me clinically in these situations researchers would have to include these complex, higher level variables.

The usual response I get is that it's too difficult to apply research methodology reliably to variables like that. My response is it's too hard to apply your research to my clinical practice when you don't include variables like that. Sometimes this argument progresses to the researcher telling me that problems like that are the "art" of psychiatry, not the "science." If researchers going to disavow relevance like that, please stop making so many immodest claims of causality and relevance, stop overemphasizing oversimplified flow charts and treatment guidelines, and stop pretending that evidence based practice is more than paint-by-numbers art.

I believe that I am a more effective psychiatrist now than when I was younger (mostly because my patients have been good guides). I attribute most of that increased effectiveness to better listening, engagement, relationship building, toleration of sticking with people even when they continue to suffer and don't follow my advice, and motivational skills. Research tends to label these factors as either "non-specific treatment effects" or "placebo responses" and looks for ways to weed them out of studies. Why is my ability to listen any less specific than my choice of SSRI? If we're honest, it isn't really less specific, it's just harder to quantify and study. Carl Rogers would have claimed that the only specific

healing factors are accurate empathy, authentic expressions of emotion, and genuine caring. The older I get, the more I think he's right. A general unwillingness to seriously study the factors that I value the most, limits my valuing research.

In most studies the "placebo response" is just about the same size as the additional "real" treatment effect. Apparently, the placebo response to pills is actually growing in America. My guess is it's as a result of direct to consumer advertising that has increased our society's belief in the effectiveness of pills. Placebo response is generally dismissed as a nuisance to research. I suspect most researchers think of it as something like fooling people into thinking that saline syringe is full of morphine, effective mostly because people are gullible, trusting, and weak, best left to P. T. Barnum. An alternate, more respectful, view is that the placebo response reflects the ability of people, consciously or unconsciously, within a potentially healing relationship, to activate internal self-healing biological processes.

At this point, neuroscience, and indeed all of medicine, is struggling primarily with conditions for which it is difficult to identify clear exogenous pathogens. Most of our current conditions seem instead to reflect some internal imbalance, perhaps a failure of homeostatic feedback mechanisms, a pathological adaptation to changes or stressors, or an internal inability to maintain a healthy balance as we develop or age. For conditions like that, our ability to find helpful medications depends more on our ability to alter internal processes, balances, and self-healing than to attack an "underlying cause" or a presenting symptom. We're not very good at that…except through placebos. I'd suggest that a serious study of the mechanisms of the placebo response (and placebo side effects) could lead to a whole new desperately needed field of pharmaceutically aided self healing.

I was taught in medical school that the one of the most robust treatment effects in all of medicine is the response of people with schizophrenia to antipsychotics. This wasn't because antipsychotics are so effective, but rather because placebos were so ineffective. The implication was that schizophrenia is a real, biological condition, whereas some of those depression and anxiety people are just faking. It is almost universal now to conclude that people with real illnesses need medications and respond to them. Recently I started wondering about an alternative explanation. What if, as it seems to me in daily practice, people with schizophrenia have difficulty making connections with people who could be potentially healing and therefore don't trigger their internal healing mechanisms so they don't respond well to placebos. It makes me wonder – do people with schizophrenia have delusions because they are difficult to connect to and influence or as is more commonly assumed, are they difficult to connect with and influence because they are delusional? Anyone care to do a serious study? There would be "specific" implications to the answer for case managers, cognitive behavioral therapy therapists and prescribers dealing with "noncompliance" everywhere.

Here are a few other specific questions I'd like to see studied about "non-specific factors" in medication effectiveness:

1) *How's the relationship between the doctor and the patient?* People tend to stay in treatment and do better with doctors they feel listen to them, care about them, and respect them,

because they in turn respect, trust, and work with their doctor. How do patients feel about their doctors?

2) *How much does the patient understand and believe in the medications?* I'm not asking if they signed a consent form. I'm asking if they internalized an explanation of how the medications would specifically help them improve their lives. People may comply with medications for awhile out of obedience alone, but long term treatment depends on really believing that they help. What are the patients' measurements of success?

3) *Are the medications improving people's lives?* Our overall purpose is not just symptom relief, but helping people have better lives. Many of our patients are unemployed, unmarried, and often substance abusing. Do the patients get jobs, girlfriends, or sobriety (or money, housing, education and legal assistance)? Are the medications directly linked to removing barriers to achieving goals the patients come in with?

4) *Were the medications integrated into other services and supports?* Medications alone are rarely an effective treatment. Integrating them into a case management team and including rehabilitation, psychoeducation, and substance abuse treatment as well as quality of life services and supports like supportive housing, employment, and education usually works better. Are medications linked to other services that promote the same goals?

5) *Were the medications part of the patients' recoveries?* Recovery based services are more effective than custodial based services. Recovery solidifies improvements and increases self-responsibility for treatment. Did the patients improve on either internal, subjective measures of the recovery process (e.g. hope, empowerment, self-responsibility, or attaining meaningful roles) or external indicators of recovery (e.g. engagement, risk reduction, increased skills and community supports)?

As a recovery oriented psychiatrist my "gold standard" for clinical applicability is: How does the intervention you're studying effect people at different stages of recovery grow and move forward to higher levels of recovery? To achieve that, researchers would have to evaluate people instead of illnesses, include interpersonal interventions and self healing processes, and assess subjective, internal outcomes and external quality of life outcomes.

2) Engagability of research products:

My favorite neuroscience writer, although I've never seen a single published journal article written by him, is Oliver Sacks. There are a few things about the way he writes that I think could be profitably applied to journal articles.

Firstly, I admire the historical reviews that he includes in each of his case studies. He brings us along as he explores what wisdom and foolishness other people, both clinicians and researchers, have discovered as they have tried to understand the workings of the brain that apply to his case. He includes all kinds of knowledge and actively evaluates their usefulness as he goes along. This is in striking contrast to the normal "review of the literature" that introduces journal articles, that is usually nothing more than a string of literature citations, usually including the authors themselves, the more recent the better, that

in the end seem more designed to prove that this article should be published than that this article will help treat patients. I think the format of journal articles should be changed from our current lists of supportive citations to a true exploration of clinical knowledge. By mimicking the process clinicians go through trying to expand our expertise to help a particular patient, each article would be "meeting us where we're at" and considerably more engagable.

Secondly, in every case study he includes his strong efforts to understand how the patient feels who has this condition (For example, what must it be like not to remember what year it is, or your own past, or what your wife's face looks like?) and his own emotional reactions to the patient and their family. These passages in his case studies are what endear him to audiences everywhere (despite his lack of substantial personal charisma). I think that every journal article, alongside the methods and material sections should have a section for patients' and evaluators' emotional reactions.

These emotional reactions have been systematically removed from articles to increase the impression of scientific objectivity. I don't think it even serves that purpose well. Wouldn't that be the same as clinicians taking the approach that transference and countertransference can be eliminated, not through thoughtful self and peer disclosure and examination, but by simply ignoring their existence (admittedly a growing trend)? It is easier to see how researchers' personal feelings influence their outcomes when they study highly emotional topics. (For example, I went to a symposium where data was presented by two different groups, one showing that it is psychologically damaging for a woman to have an abortion and the other one showing it is psychologically damaging for a woman to have an unwanted child. In another symposium a group of Midwestern researchers showed that homosexuals have weaker relationships and emotional commitments to their partners suggesting that they're not experiencing the same as strong a bond as in heterosexual love and marriage were challenged by a group of homosexual researchers from San Francisco who showed that the social supports to maintain committed loving relationships were missing for homosexuals and often replaced by degrading social reactions, thus making it remarkable that homosexuals could achieve the degree of commitment they often do. It was only because I heard them speak in person, rather than read their articles, that I could assess their emotional investment in their subjects.) I think it would help researchers themselves to be forced to write about the emotional aspects of their work.

From a clinical perspective, the most important emotional data I need is how the people who dropped out of the study felt. The largest obstacle I face in helping anyone with anything is the likelihood that they will "drop out" – either they'll stop seeing me entirely or they won't do the treatment. It is of very little help to me to have an effective treatment that my patients won't follow through with. At present, most articles handle drop outs by statistically analyzing their demographics and concluding they aren't different form the subjects who remained in the study and therefore their absence hasn't biased the evaluation of the treatment. I doubt that's ever true. Even if the drop outs aren't "statistically" different, they are very likely "subjectively" different. I believe that articles should include a lengthy discussion of the feelings of drop outs (and excluded people), because that would guide me with the patients I 'm actually working with.

Probably, the most important difference between Oliver Sack's writings and the vast majority of journal articles is that he is usually doing case studies rather than population studies. (The few "case studies" included in journals today strike me more as poor man's population studies, "suggesting further research" rather than as sophisticated, serious works, creating their own knowledge.) Case study research needs to be revitalized as legitimate and valuable research.

We all know the stories of how the first drugs in any class were mostly discovered by accident. (I believe the scientific term for this is "unexpected positive deviance.") Our present population studies systematically reject these "outliers" and, perhaps as a result, very few truly new therapeutics or classes of drugs have been invented in decades.

Neuropsychiatry is an impressively complicated subject, with so many variables, that individuality is almost guaranteed. Lumping people together (in increasingly dubious groups – I recently sat in on a planning meeting for a study of psychoeducational approaches for manic depressives with drug abuse where they expected most of the subjects to have "Bipolar II" because "pure Bipolar I" would be too hard to collect) must radically compromise our ability to actually understand the true complexity involved. A great deal of the growth of my professional knowledge over my career comes not from reading population studies, but from investigating my patients as "case studies." (For example, I now know that many people are contacted by dead relatives without any diagnostic significance, the sound of water in a shower can make voices worse, and that many hallucinations have a quality of self preservation that makes them actively work against my efforts to eliminate them, that doesn't make sense if they're just the product of a chemical imbalance.) I think that the work of population researchers would be greatly enriched if they had to do serious case studies periodically as well.

I also think that many of the weaknesses of DSM are from its producers' reliance on population studies instead of case studies, a trend begun by my "psychoepidemiology" teachers at Washington University with the original syndromic diagnostic descriptions in the Feighner criteria. Since our research population studies are most commonly diagnostically based, rather than based on a personal characteristics, we are inadvertently enhancing the blurriness of our findings. I am more likely to be able to apply a nuanced insight gained from a detailed serious case study to a patient in front of me, than to be able to apply a statistically significant finding about the response of a large diagnostic group that my patient only loosely resembles.

Overall, I think that there are three general ways to help people who have serious, long term illnesses: 1) I can directly treat their illness so it is less troublesome, 2) I can help them learn ways to cope with and adapt to their illness, even if it can't be "cured", and 3) I can help them have a better life in spite of their illness. Despite the "decade of the brain" and billions of dollars spent on psychopharmaceuticals, it is my judgment that over the course of my career far more progress has been made in the second two areas than the first area. The "newer" pills are overall safer, more tolerable, and easier to use, but they're not actually more powerful. CBT and 12-step were probably the most widely effective psychotherapies when I started, and they probably still are. If a hypothetical Rip Van Winkle psychiatrist woke up now after sleeping for 20 years, I could probably catch him up in a day on direct illness treatment advances. On the other hand, the advances in the other two areas have been much more

robust including self-help, WRAP, rehabilitation, recovery, supported housing, housing first, outreach and engagement, motivational interviewing, harm reduction, supported employment, integrated dual diagnosis treatment, cultural competence, team case management, consumer advocacy, peer mentoring, advanced directives, and client-driven, goal directed, collaborative treatment. He'd have to literally transform himself to take advantage of all those advances.

Unfortunately, most researchers are not involved in any of those advances and, I fear, are mostly unaware of them. Unfortunately, most practitioners are not involved in any of those advances and, I fear, are mostly unaware of them. Tragically, most patients and their families are not involved in any of those advances and, I fear, are mostly unaware of them.